

ORIGINAL ARTICLE

Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service

Barbara A Jack, Mary R O'Brien, Joyce Scrutton, Catherine R Baldry and Karen E Groves

Aims and objectives. To explore bereaved family carers' perceptions and experiences of a hospice at home service.

Background. The increasing demand for the development of home-based end-of-life services is not confined to the western world; such services are also emerging in resource-poor countries where palliative care services are developing with limited inpatient facilities. Despite this growing trend, studies show a variety of interrelated factors, with an emphasis on the availability of informal carers and their ability to cope, which can influence whether terminally ill patients actually remain at home. A hospice at home service was developed to meet patients' and families' needs by providing individually tailored resources.

Design. A qualitative study.

Methods. Data were collected by semi-structured, digitally recorded interviews from 20 family carers who had experienced the service. Interviews were transcribed verbatim and a thematic approach adopted for analysis.

Results. All participants reported a personal positive impact of the service. Family carers commented the service provided a *valued presence*, they felt *in good hands* and importantly it helped in *supporting normal life*.

Conclusions. The impact of an individualised, targeted, hospice at home service using dedicated, palliative care trained, staff, is perceived positively by family carers and importantly, supportive of those with additional caring or employment commitments.

Relevance to clinical practice. The emergence of hospice at home services has resulted in more options for patients and their families, when the increased amount of care a family member has to provide in these circumstances needs to be adequately supported, with the provision of a flexible service tailored to individual needs and delivered by appropriately trained staff.

Key words: carers, home-care services, interviews, palliative care

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What does this paper contribute to the wider clinical community?

- Family carers require individually tailored support.
- Respite for family carers is vital.
- Ongoing regular assessment of family carers needs is recommended.

Introduction

Promoting patient choice in treatment, management and location of care, along with initiatives to reshape primary care provision to reduce hospital in-patient episodes, is core to several UK policy drivers (Higginson *et al.* 2013). Implicit in the Department of Health (DH) (2008) End of Life Care Strategy is the desire to support patients to be cared for, and to die, in the place of their choosing. This strategy acknowledges the stated preference among the general public to remain at home and preferably die there (Shepperd *et al.* 2011). This increasing demand for the development of home-based end-of-life services is not confined to the UK and other parts of the developed world, for example Australia (Hall *et al.* 2014), but is also emerging in resource-poor countries where palliative care services are developing with limited inpatient facilities, due to cultural norms and financial constraints (Economist Intelligence Unit 2010, Joad *et al.* 2011). However, despite this growing trend, studies show a variety of interrelated factors, with an emphasis on the availability of informal carers and their ability to cope, which can influence whether terminally ill patients actually remain at home (Gomes & Higginson 2006). The importance of family carers (National Institute for Clinical Excellence (2004), adopted by Payne and Morbey (2013), regards family carers as those with a close social and/or emotional, but not necessarily a blood relation to the patient), is emphasised within the call to recognise the critical role played by them as co-workers within the care team (DH 2008).

It is estimated that in the UK there are over 6.5 million people acting as unpaid carers for friends or family members, of which approximately 500,000 are in an end-of-life phase (NCPC 2012). This conservative figure, due to a hidden network of care provided by people not known to health and social care services, is estimated to rise and, importantly, will comprise an ageing population many of whom have their own health issues. This population of family carers is also affected by changes in family and household composition, geographical movement, European migration and increased divorce rates with the resulting challenge of adults having to care for parents in different locations and homes (Leadbeater & Garber 2010, Payne & Morbey 2013). There is also the emergence of the 'sandwich' generation of carers faced with numerous challenges from having dependent children and/or grandchildren along with older parents needing care. Furthermore, changes in the UK retirement legislation will increase the number of people working further into older age, again providing

challenges for remaining in employment while acting as a carer (Carers UK 2012, 2013).

Despite the emphasis on promoting the role of family carers in helping dying patients to remain at home, it is widely acknowledged that carers are unprepared for the role and the multiple challenges they may face including those physical, psychosocial and financial (Hudson & Payne 2008, Lucas *et al.* 2008, Hall *et al.* 2014). This unpreparedness of the family carers is not confined to the western world, with a recent Indian study (Joad *et al.* 2011), highlighting an increased need to support family carers. These challenges, if not addressed, can result in hospital admission for the patient due to increased carer burden (Gomes & Higginson 2006, Jack & O'Brien 2010, Leadbeater & Garber 2010). What remains is a gap in knowledge as to what appropriate support is required during the dying phase (Grande *et al.* 2009).

Background

There are approximately 129 Hospice at Home (HAH) teams in England, Wales and Northern Ireland (Help the Hospices 2012), however, no single model of a HAH service exists. Variations include out-of-hours services, rapid response teams and community teams all comprising differing elements of care provided by medical staff and a mixture of qualified and unqualified nursing staff (Stosz 2008). This lack of an agreed definition of a HAH service has implications for future service development, and in an attempt to address this national standards are being developed (Bell *et al.* 2013). However, this lack of service consistency, along with the challenges of undertaking robust trials with patients at the end-of-life, has resulted in a limited evidence base, with a recent Cochrane review identifying only four trials that met their inclusion criteria (Shepperd *et al.* 2011). Studies involving healthcare professionals have generally shown a positive impact of these services (Lucas *et al.* 2008). Some early studies sought the views of bereaved carers of HAH services, reporting generally positive outcomes (Exley & Tyrer 2005, McLaughlin *et al.* 2007). More recently, a systematic review that incorporated HAH services, included nine specific studies reporting how the service was valued by patients, families and healthcare professionals. However, the wide range of services and team composition impacted on the generalisability of the findings (Candy *et al.* 2011). Clearly, there remains a need to identify which elements of such services are providing optimal benefits and for whom (Higginson *et al.* 2013).

The hospice at home service

Situated in north west England, serving a population of approximately 235,000, in a mixture of semi-rural and urban residential areas, the Hospice provides ten inpatient beds and day services. To complement this provision, and to support people to remain at home and to die at home if they wish, the HAH service was established in 2009. The service comprises: *Hospice Aides* (registered nurses and healthcare assistants who have had end-of-life care training), *Accompanied Transfer Home* and *Crisis Intervention*. Patients with advanced progressive illness who are on the Gold Standards Framework Register, eligible for the DS1500 form (enables the patient to access non-means tested benefits at end-of-life) and who wish to remain at home can be referred to the service by healthcare professionals. The patient would already be receiving care from the primary care nursing team and other care agencies, e.g. social services, private agencies (Jack *et al.* 2013).

The development of the service and evaluation of its impact on healthcare professionals have previously been reported (Baldry *et al.* 2011, Jack *et al.* 2013). Healthcare professionals commented on how the service helped support family carers to continue coping with their caring responsibilities. This paper focuses upon family carers' experiences and perceptions of the service.

Methods

The aim of this study was to explore family carers' experiences and perceptions of the HAH service.

Design

To meet the aim of the study a qualitative approach was selected drawing upon a naturalistic interpretative approach (Ritchie & Lewis 2003). This enabled an in-depth rich understanding of the participants' experiences and perceptions of the HAH service (Robbins 1998, Polit & Beck 2009, Topping 2010).

Participants

A purposive sampling approach was employed (Polit & Beck 2009), with specific inclusion criteria: participants were aged over 18 years and had been the main carer of a patient who had received the service. Furthermore, consideration was given to the time since bereavement. No formal guidance exists regarding an appropriate time frame before

contacting bereaved family carers to participate in research, which is the subject of much debate. Drawing upon studies which have explored the issue, a minimum of three months since bereavement was regarded as appropriate to give consideration to the need for sensitivity and memory recall (Addington-Hall & McPherson 2001, Beck & Konnert 2007).

An open invitation was placed in various public outlets including: local free papers, Hospice website, carer organisations, GP practices, Hospice facebook page and Hospice shops, in addition to the normal Hospice media distribution routes. Former family carers who had experienced the service were invited to contact the research team, following which information about the study was sent to them before recruitment took place. Thirty people responded to the invitations and eventually 20 were recruited (see Fig. 1). Brief demographic details of the final sample are contained in Table 1. Home death occurred for 18 of the family members, the remaining two had unplanned hospice admission at the end-of-life.

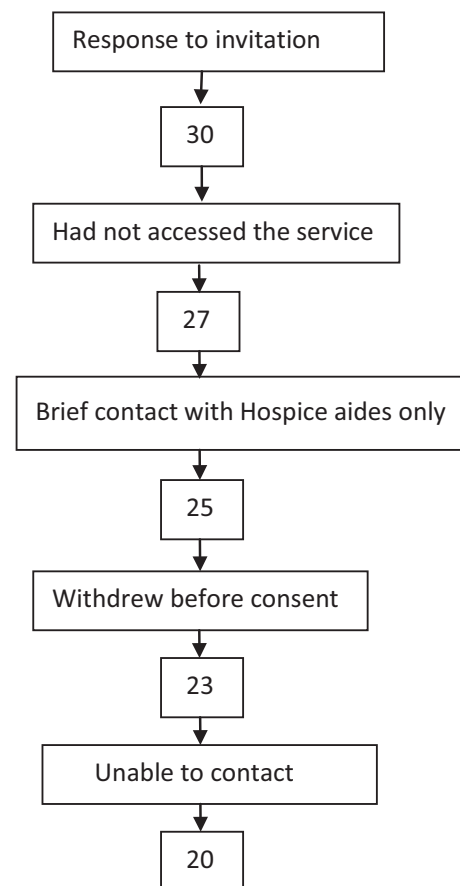


Figure 1 Study recruitment.

ID	Sex	Relationship	Age of respondent	Age of deceased	Diagnosis	Lived with deceased or not
1	F	Wife	60–69	60–69	Cancer	Yes
2	F	Daughter-in-law	50–59	80–89	Cancer	No
3	F	Daughter	20–29	50–59	Cancer	Yes
4	M	Husband	50–59	40–49	Cancer	Yes
5	M	Husband	70–79	70–79	Cancer	Yes
6	F	Daughter	60–69	80–89	Cancer	No
7	M	Husband	60–69	60–69	Cancer	Yes
8	F	Wife	80–89	90–99	Cancer	Yes
9	F	Mother	50–59	20–29	Cancer	Yes
10	F	Wife	70–79	70–79	Cancer	Yes
11	F	Wife	60–69	70–79	Heart failure	Yes
12	F	Wife	60–69	60–69	MND	Yes
13	F	Wife	60–69	60–69	Cancer	Yes
14	M	Husband	80–89	80–89	Cancer	Yes
15	M	Husband	70–79	70–79	Cancer	Yes
16	F	Daughter	50–59	70–79	Cancer	No
17	F	Daughter	50–59	70–79	Brain tumour	No
18	F	Wife	80–89	80–89	Cancer	Yes
19	F	Wife	70–79	70–790	MND	Yes
20	F	Daughter	40–49	70–79	Cancer	No

MND, motor neurone disease.

Table 1 Demographic details of the final sample

Ethical considerations

The University Faculty Research Ethics Committee approved the study as did the Hospice Executive Team. Ethical considerations were adhered to throughout the study. Permission to use direct quotations was obtained and participants advised that all identifying data would be removed during transcription. Consideration of the sensitive nature of the topic under exploration was noted and all participants were provided with a contact at the Hospice if they wanted further support. The researchers undertaking the data collection had a background in nursing and extensive qualitative research experience.

Data collection

Qualitative, digitally recorded, interviews were adopted for the study. A topic guide was developed from the previous evaluation of healthcare professionals' views of the service (Jack *et al.* 2013). The interview was conversational in style and semi-structured to allow the interviewer to address themes relevant to the research questions while also allowing them to follow relevant avenues of enquiry opened by the participants (Oppenheim 1992, Polit & Beck 2009).

Bereaved carers were involved in creating study materials with two taking part in pilot interviews to develop, and

allow refinement of, the interview guide. All interviews were conducted between January–March 2013, by two of the research team (BJ, JS) and lasted between 25–50 minutes. Participants were offered a choice of location for the interview including home, the Hospice or the university, with all three venues being selected, although the majority were at home.

Data analysis

Interviews were transcribed verbatim and a thematic approach adopted incorporating a number of stages to systematically organise, reduce, refine and ultimately analyse the data (Braun & Clarke 2006). Each transcript was read and re-read until a thorough understanding of the content was achieved and commonalities and differences among the accounts were identified as patterns, or themes, within the data (Green & Thorogood 2004). Categorisation of the data followed whereby these early themes were formed into descriptive codes and the data were subsequently reduced to provide support for the initial conclusions (Miles & Huberman 1994). Coding was undertaken independently by two researchers (BJ, MOB), before meeting with a third (JS) to discuss and ultimately agree on the final coding frame as a means of increasing the rigour of the analysis (Saks & Allsop 2007). The analysis continued as these

themes were defined and redefined ensuring all data were represented (Miles & Huberman 1994).

Results

Although the service comprised a number of elements, not all of these were commented on by our respondents as their relatives may not have experienced all aspects of the service. There was a clear emphasis on the element of the hospice aides (day and night service) within the data hence that is the focus here. A number of issues concerning the impact of the service were evident within the data. The themes are presented here supported by direct quotations from participants emphasising that the findings have emerged from, and are grounded within, the data.

Impact on the carers

The impact of the service on the carers themselves dominated the interviews. Three key themes were apparent within the data: *a valued presence*, *in good hands* and *supporting normal life*.

A valued presence

Without the service participants stated that they would have felt more vulnerable, lost and alone:

If I didn't have that service... I would probably feel very, well *more* vulnerable than what I felt – although I did feel vulnerable – a lot more vulnerable, and a lot more anxious, and probably very alone and lost, and isolated. (Respondent 4, Husband aged 50–59)

There was a distinct sense that the service provided enormous benefits, for the families, with comfort drawn from the presence of HAH staff within the home:

And I kind of knew when they were there, that she would be fine. (Respondent 20, Daughter aged 40–49)

However, knowing that someone else was there with the patient was not just comforting, it was also reassuring. Participants commented that they frequently received validation from the staff that what they were doing, for their loved one, was right:

Made me feel that we were doing everything we should do, there's always a doubt in your mind that "oh, what if?", "should I do this; should I do that?", but they allowed you to stand back and think "actually, there isn't anything else that we can do; this is the best it is...." (Respondent 1, Wife aged 60–69)

During bad times when carers were struggling to cope with their situation, knowing that a visit was scheduled helped them to carry on and gave them the confidence to continue in the caring role:

I mean there was some days when you feel you can't cope, but you've got to cope, and you've just got to get on and do it, but on the days when I knew [HAH] were here, it made a big difference, gave me more confidence and I certainly felt able to cope when they were here. (Respondent 7, Husband aged 60–69)

It certainly made my life easier, made it easier to cope with and gave me a bit more peace of mind and, as I say, reassurance. (Respondent 6, Daughter aged 60–69)

The final moments of a loved one's life is a traumatic and difficult time for many; having an aide present in the home certainly helped one family to experience a good death:

I valued that somebody was here the night he died, because the nurse called us when she thought it was time, so my daughter and I were with him. (Respondent 18, Wife aged 80–89)

In good hands

For some participants, being enabled to have, even brief, periods away from the responsibilities of caring was regarded as extremely important. Hospice aides (day staff) allowed carers to safely leave the patient while they undertook everyday activities that would otherwise not have been possible:

They saved my life... I could go out without worrying. (Respondent 12, Wife aged 60–69)

Many participants spoke of a confidence that exuded from the staff, which helped them to relax knowing that their loved one would be cared for properly:

It was just something about them, there was just something that, the [HAH] staff had like – and the ones that I thought would be fantastic for the service – they all had this like "air", I don't know what it was about them, I just felt "mum's really going to get cared for with you, I don't need to worry". (Respondent 3, daughter aged 20–29)

It did help, 'cause I knew she was in good hands, I knew the [HAH] nurses were here and everything would be alright while they were here. (Respondent 7, Husband aged 60–69)

It wasn't merely their presence, which was noted, comments were made regarding the level of experience and knowledge that the nurses had. There was a distinct sense

that carers had peace of mind, as did the patients themselves, as a direct result of having staff on hand who were, not only caring, but also extremely capable:

I mean, I had the comfort of knowing that she was with somebody ... of sufficient experience ... to know what to do if anything turned out for the worst you know, and it was good to know that I was going out for a couple of hours to get the shopping and what not and they, that person was here with her which was a of comfort to me and her as well. (Respondent 5, Husband aged 70–79)

Carers commented about the aide service which they regarded as something which kept them afloat in difficult times. The relief provided was palpable:

I just felt like I didn't have to worry 'cause they were here; that's what it felt like, it was like having the lifeboat, isn't it, or the safety net. (Respondent 9, Mother aged 50–59)

Knowing that their relative was in good hands meant that carers were able to take some time for themselves without feeling guilty:

I was just very grateful that somebody could come and give me you know a bit of a lift really and give me some time to just have a sleep and time to just get out into the fresh air and see normal people. (Respondent 10, Wife aged 70–79)

For some carers, however, the decision to accept help at all was a difficult one to make. There was a feeling among participants that care should be provided directly for the patient and not for the carer. In fact it was apparent that some participants actually felt guilty at accepting help aimed at making their lives easier:

I should be doing this, the whole point of bringing her home was you know, I should be doing this. (Respondent 16, Daughter aged 50–59)

A sense of duty pervaded many of the accounts, with carers expressing the view that it was not easy for them to hand over caring tasks which they felt they should be doing:

It's very difficult to let go of what you think is your responsibility. (Respondent 16 daughter aged 50–59)

One key aspect of knowing that their loved one was in good hands focused on the fact that carers were given time for themselves. Daytime hospice aides allowed carers to resume some form of 'normality':

I got people sitting with her so that I could go and do the shopping and this and that and the other, which again, was a very welcome bit of relief. (Respondent 5, Husband aged 70–79)

The night-time Hospice aides also provided invaluable support for carers who felt able to carry on with daytime caring if they were well-rested at night:

I don't think it's simply for his [patient's] benefit, I think it's for the benefit of the family, because you cannot look after somebody 24 hours a day, and to actually be able to have some rest at night is paramount so that during the day you can actually be there, support them and be "awake"; I do not know how people manage without some sort of support at the end of the day. (Respondent 1, Wife aged 60–69)

Having night-time Hospice aides was vital for one couple who had been together for 60 years and did not want to be parted. Their daughter-in-law recalled the effect on her father-in-law (the main carer) of trying to be there for his wife around the clock:

Because she'd got a hospital bed and so she was in the lounge and he had even tried to put a little mattress down beside her so he wouldn't leave her... so when the sitting service came it was peace of mind for us because he was getting confused and not looking after himself as much, so that wasn't helping anybody. So once the sitting service came in and he, he would feel confident enough then to go to bed, so he was able to sleep and that helped him not being as confused. So he was getting sleep and all the family were getting peace of mind as well. (Respondent 2, Daughter in Law aged 50–59)

There were also occasions when night-time Hospice aides helped out with domestic chores, which had a two-fold beneficial effect. Not only were the chores completed, but it provided the opportunity for carers to be able to spend quality time with their relative at such an important period as they neared the end of their lives:

The [HAH] night girl, she did the ironing for me – it sounds like such a simple little thing – but it meant the next day instead of sitting doing the ironing I took mum out for the day, and just being able to do that was just ... it was just *so nice*. And it's one of my favourite memories as well, and she did that a few times for us... it just meant that we made the most of that time. (Respondent 3, Daughter aged 20–29)

Supporting normal life

It was apparent from the experiences reported by our participants that aspects of the HAH service could be instrumental in helping family carers to continue with their 'normal lives'. In particular it was noted that younger carers, providing assistance to their parents, could be torn between their caring and family responsibilities (the sandwich generation).

The availability of Hospice aides to sit with patients helped to relieve the strain on carers and allowed them to continue with 'normal' family life activities:

That's the thing, 'cause there was always the tug, you know between rugby practice or going and looking after M – and obviously M would win out every time – but it meant that the boys could carry on with their activities. (Respondent 2, Daughter-in-Law aged 50–59)

So they arrived at 12 o'clock and stayed till four so I phoned my husband up and said 'do you want to take me out on a date' and he came down and we went out for lunch for a few hours. It was lovely, yes, and obviously I had just abandoned [husband] and left him at home, not that he minded anyway about that but it was nice to get out and have lunch. (Respondent 16, daughter aged 50–59)

Families often endure uncomfortable conditions and sleepless nights when supporting each other in looking after a dying family member. The presence of night-time Hospice aides meant that adult children were able to remain in their own homes at night knowing that their parent was being looked after:

If I had not had that [HAH] at night, my children would have had to come here and sleep on the floor while I was in the bed, or sit in the chair. (Respondent 15, Husband aged 70–79)

Family carers were given *time* when the Hospice aides were present. One respondent, who was caring for his wife as well as their young children, reported having the time to be able to focus on the children when he knew his wife's needs were being met:

It gave me a little bit more time to do things on my own, I could gather my own thoughts and rationalise things [...] it would give me a bit more time to think about, you know what the children needed to do the next day – or the day after or their homework [...] so I think it's benefited the family, you know, all of us. (Respondent 4, Husband aged 50–59)

For some participants the service meant more than merely providing care for a family member, it made the difference between being able to continue to run a business and losing it altogether:

Without them I probably would have lost, you know I would have had to give up work or something and then being self-employed and it being your own business... it's not something you can get back. (Respondent 20, Daughter aged 40–49)

Furthermore, carers in paid employment could concentrate on their work knowing that their loved one was being

cared for, which has obvious benefits in terms of maintaining their income:

Well it was better for me because I could go to work and relax. I didn't have to keep constantly ringing up. (Respondent 20, daughter aged 40–49)

It enabled them (daughters) to go back home to their own homes – and go to work and go back to work properly, not the fear of being called out to look after us. (Respondent 11 wife aged 60–69)

Limitations of the study

Criticisms can be levelled against the retrospective design and the potential for recall bias. A prospective longitudinal study that includes patient and carer reported outcomes would be invaluable. Although this model of a HAH service has not been formally evaluated in other settings, lessons from its composition and delivery are informing the development of other similar services in the North West Region. Clearly a randomised controlled trial is required to establish the evidence base for models of HAH services.

Discussion

This paper has reported bereaved family carers' perceptions of having experienced one element of the HAH service, namely, HAH aides, in the care of their relative. The participants included a variety of relationships and ages, thus providing an insight into a broad range of situations, fairly typical of the population. The findings have shown the additional support of a dedicated HAH aide has a positive impact for family carers and in addition, the family carers' own family unit and employment responsibilities. No criticisms were raised about the HAH service, but several respondents who had experienced agency care staff made negative comments around their punctuality and level of professionalism (there were no reports of poor care).

The impact of the service on the carers reflects the findings from a recent study confirming the value of respite care, particularly at night, during the terminal phase (Ewing and Grande 2013). However, here this finding was coupled with the high level of confidence (*in good hands*) that the carers had in the Hospice aides. In addition, this respite was highly valued by those carers who had other family caring responsibilities or work commitments, enabling them to carry on with their lives where possible. This was similar to a finding by Hall *et al.* (2014) where carers had reported juggling caring with employment commitments. Interest-

ingly, this finding of need for normality was reported by the Princes Royal Trust for Carers charity, older carers (aged over 60 years) survey in 2011. The respondents reported the value of respite care, however, there was a caveat that they needed to have confidence in the quality of care that would be provided, due to a lack of good quality services to look after their relative (Princess Royal Trust for Carers 2011).

It is known that carers need assurance that they are doing the right thing (Connolly & Milligan 2013). One of the unexpected findings in our study was the importance the carers placed upon *validation* of the care they were providing. This reassurance, which had the effect of increasing their confidence, was widely reported. It raises several areas for consideration, including the extent of experience people have of actually caring for sick family members and whether there is a need for training to be given. Leadbeater and Garber (2010) suggest that short training is vital especially for those embarking on a prolonged caring journey with, for example, neurological conditions. Findings from a recent Scandinavian study, of a preparedness to support programme, showed positive impact on carers including an increase in their confidence (Henriksson *et al.* 2012). This notion of *validation* suggests that targeted interventions, to enable carers to gain confidence, would be worthy of further exploration.

Conclusion

The impact of this one element of an individualised targeted HAH service, using dedicated staff who have undergone palliative care training, is perceived as having a positive impact on family carers, while also supporting those with additional caring or employment commitments. It is suggested that the HAH aide service is helping patients to remain at home for the last days of their lives and is thus supporting the implementation of the End of Life Care Strategy aim to promote patient choice (DH 2008). Supporting family carers is clearly vital, particularly with an increasing ageing population where carers may have their own health needs. Similarly, for the 'sandwich' generation of dual carers and those in employment, consideration needs to be given to what support is appropriate for their

needs. An individual package of care based upon ongoing assessment of carers' needs is undoubtedly required. For end-of-life care, this re-assessment is vital, as the caring role changes over the disease trajectory. Adopting the philosophy of recognising family carers as co-workers and supporting them in this role, will help to facilitate carer empowerment and is clearly required if their needs are to be recognised and ultimately met.

Relevance to practice

The policy driver to support patients to be cared for and to die at home, if they so wish, has resulted in the reconfiguration of hospice services. The emergence of HAH teams and increased day care interventions have resulted in more options for patients and their families. However, increasing the amount of care a family member has to provide in these circumstances needs to be adequately supported with the provision of a flexible service tailored to individual needs and delivered by appropriately trained staff. End-of-life care training is paramount to the success of these services to ensure optimal care for the patients and their family carers.

Disclosure

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit (www.icmje.org/ethical_1author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

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Conflict of interest

KEG is employed at the hospice where the service was developed. CRB was previously employed at the hospice.

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